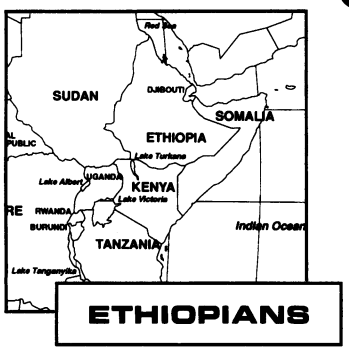
- Since 1980, an estimated 75,000 Ethiopian refugees have arrived in the United States
- The 1975 overthrow of Emperor Haile Selassie by a Marxist regime, followed by a period of intense political repression, caused this population movement
- Ethiopia has a highly diverse population



Cross-cultural Medicine
A Decade Later

Medical Disclosure and Refugees
Telling Bad News to Ethiopian Patients

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The strong value in American medical practice placed on the disclosure of terminal illness conflicts with the cultural beliefs of many recent refugees and immigrants to the United States, who often consider frank disclosure inappropriate and insensitive. What a terminally ill person wants to hear and how it is told are embedded in culture. For Ethiopians, "bad news" should be told to a family member or close friend of the patient who will divulge information to the patient at appropriate times and places and in a culturally approved and recognized manner. Being sensitive to patients' worldviews may reduce the frustration and conflict experienced by both refugees and American physicians.

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Until recently, physicians in the United States tended not to disclose the fate of terminally ill patients, even when it was obvious that the patients were going to die.[1] In the past two decades, however, there has been a dramatic change in the policies of American physicians regarding disclosing the prognosis to terminally ill patients.[2-4] The most debated issue in disclosing or withholding information concerns the diagnosis of cancer and the prognosis of imminent death when there are no further treatment options. This shift of American physicians toward disclosure is attributed to underlying changes in the social structure of the US health care system, the demands of patients to know and to decide about their medical care, the legal obligation that requires that patients understand the nature of their disease before consenting to an operation or experimental therapy, and societal questioning of physicians' authority.[3,5]

American physicians' practice of disclosure contrasts with dominant biomedical traditions in other societies.[5] For example, Italian physicians withhold a diagnosis of cancer to sustain hope and protect the patient from bad news. The disclosure of terminal illness is viewed as an important factor in a patient's decline and a cause of further harm.[6,7] In Japan, as a general rule, physicians do not tell patients they have cancer. Even the late Japanese emperor was not told that he had pancreatic cancer.[8] Japanese physicians think that telling patients they have a grave diagnosis will only hasten their death.[8,9]

Disclosure in the American cultural context is essential to obtain consent for treatment, to challenge the disease, and to be in control of the situation. Furthermore, being aware of one's condition affords autonomy and the ability to make decisions and to master one's fate.[7,10] This strong value placed on the practice of open disclosure of terminal illness in the United States conflicts particularly with the cultural beliefs of many of America's recent immigrant and refugee groups, who consider frankness in medical disclosure inappropriate and cruel.[11]

In this article, I explain some Ethiopian cultural reasons for preferring nondisclosure of terminal illness, using a few case examples of Ethiopian patients in the United States. I also suggest some guidelines to minimize conflict between American physicians and their refugee patients. The suggestions are based on my experience as a member of the Ethiopian community and on discussions with Ethiopian patients and families and with American and Ethiopian health care professionals.

Case Examples

Case 1

The patient, a 33-year-old professional married Ethiopian woman, was admitted to a university hospital for surgical exploration for an intractable gastrointestinal disorder. The patient had lived in the United States for more than 15 years, had a college education, and spoke fluent English. Before the patient and the physician agreed to the operation, she had three appropriate tests performed, each with negative results. The exploratory operation revealed, however, that she had stomach cancer that had spread to other organs and was impossible to remove. This finding was disclosed to her husband right after the operation. He was told his wife's prognosis was poor and that she had three to six months to live. The husband requested that the surgeon and her physician not tell the patient at the time and assured them that he would break the news to her at an appropriate time.

Although the husband had requested that his wife not be told, a day after the operation the surgeon went ahead and told her that she had cancer and that it had spread. With this tragic news, the patient fainted. After she recovered from the initial shock, the patient refused to talk further to this physician. The patient described his behavior as "cruel" and "in-

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considerate." She decided she did not want to know the extent of her illness more than she was already told and found an oncologist who was willing to accommodate her wishes. Her entire treatment regimen was then discussed only between her husband and the new physician. Neither her husband nor any other family member encouraged the patient to seek full disclosure. To do so would have taken hope away from her and discouraged her from fighting the illness. Moreover, the larger Ethiopian community would have seen it as an irresponsible and uncaring act on the part of the family members. After a year and a half of treatment, however, having outlived the initial predictions, the patient decided on her own to take part in the clinical discussion of her case and to face the facts about her condition. She was glad that she chose not to know her true condition earlier; if she had known earlier, the magnitude of her illness would have overwhelmed her and discouraged her from fighting the disease.

Case 2

The patient, a 16-year-old Ethiopian girl with an inoperable brain tumor, was admitted to a psychiatric clinic with head pain. The patient was taking several medications for the tumor. Before being referred to the psychiatric clinic, she had been in group therapy at an outpatient clinic where she was described as depressed, needy, and isolated. She did not mingle with the other young people in the group, nor was she willing to engage in discussion, particularly regarding sex. This was perceived by the therapist as abnormal because most American girls her age have a lot to ask and say about the subject. Once admitted, the patient denied that she was depressed and insisted that her major problem was the head pain. Furthermore, her family did not want her to know her diagnosis of brain tumor and had asked her physician not to tell her. Her previous psychiatrist had disregarded this request, however, and had told the patient. When her family discovered this, they interrupted the therapy and changed physicians.

The attending physicians were frustrated, claiming that her family was not honest with her. They also felt that they were blocked from communicating openly with the patient. Because the patient had lived in the United States for about nine years, they felt that she had grown up in this culture and therefore should act like an American teenager.

Case 3

The patient, a 38-year-old married Ethiopian man diagnosed with bone cancer with a poor prognosis, was admitted to a public hospital. The patient knew his diagnosis but was unaware of the poor prognosis. Because he had been in this country for only a couple of years and did not speak English, an Ethiopian interpreter was asked to assist. After a trial of chemotherapy, the cancer was deemed untreatable. The physician involved tried to disclose this fact to the patient through the interpreter, who was asked to tell the patient that there was no more treatment for him and his condition was terminal. The interpreter was able to tell the patient that there was no more treatment for him but could not say to him that his was a terminal case. The patient became distraught and asked the interpreter to tell the physician that he wanted to continue treatment. The interpreter was caught in the middle, being faced with the cultural conflict of telling the patient that he was dying. Finally, the interpreter was able to relate this fact to the patient indirectly.

These case reports show some of the day-to-day conflicts between immigrants and refugees and American health care professionals. Using these examples, I will discuss the Ethiopian core cultural values that are in conflict with American medical practice, particularly in regard to truth telling, the meaning of hope, and death and the role of the family. Readers should keep in mind, however, that variations exist within the Ethiopian immigrant-refugee communities in the United States: urban or rural origin, length of stay in the United States, level of education, gender, age, and religious differences are some of the important factors leading to diversity in this group.

Ethiopian Refugees in the United States

Compared with other immigrant groups, the Ethiopian community in the United States is relatively new and small. The exact size of the community is unknown, with current estimates varying from a low of 50,000 to a high of 75,000.[12] The lack of a reliable census of the Ethiopian population will remain a problem well into the next decade, as Ethiopians were subsumed in the "Other" category for the 1990 census. As a result, Ethiopians face being lost in the large refugee and immigrant population and their needs and concerns going unaddressed.

Before 1974 the Ethiopian community in the United States was small and scattered, with a handful of Ethiopians permanently settled. Of an estimated 3,000 Ethiopians residing at the time in the United States, 95% were students and expected to return to Ethiopia on completing their studies. The other 5% were either diplomats or associated with various international organizations. That year Emperor Haile Selassie was dethroned by a militaristic Marxist regime. Shortly after, from 1976 to 1978, in the course of consolidating political power the self-styled Marxist military government, unwilling to accommodate ideologic differences with other political organizations, unleashed a system of political repression called the "Red Terror" that took thousands of lives. The arrests and indiscriminate executions of suspected members and sympathizers of the opposition and the brutal civil war in Eritrea and Tigray forced many Ethiopians to seek refuge in neighboring and distant countries. Many Ethiopians living in the United States decided to make this country their home, and many more came and settled here as refugees. Most Ethiopian refugees have been in the United States since the 1980s, and many continue to come.[12]

Ethiopia, a country the size of California and Nevada combined, is a multiethnic, multireligious nation with more than 70 distinct languages. Ethiopia is essentially a highland country. The high plateau covers about two thirds of the country, and deep river canyons cutting through the plateau create varying ecologic environments within short distances. Due to the variable topography, there is a marked difference in the climate conditions, which range from being tropical in the canyons to temperate on the plateau, often within a few miles.[13] Despite this tremendous ethnic and geographic diversity, similar core cultural values underlie the behavior of all Ethiopians.

Most Ethiopian immigrants are from an urban background and for the most part live in major metropolitan cities in the United States—Washington, DC; Los Angeles and the San Francisco Bay Area, California; Chicago, Illinois; Boston, Massachusetts; and New York City. Demographic data indicate that there are more men than women, and 70% of the

community members are between ages 18 and 34. In the United States, at least three major Ethiopian languages are spoken among immigrants: Amharic, Tigrigna, and Oromigna. Most Ethiopian immigrants speak English or Amharic, Ethiopia's national language. A number of Ethiopians, however, have difficulty speaking any of these languages.[14] Data on English language skills show that 81% had some skills—ranging from fluent to some English—but 19% had no English skills at all.[12] Ethiopians can be found working across the entire job spectrum, from low-paying "dead-end" jobs to the demanding fields of medicine and "high-tech" electronic or computer engineering. Most, however, work in a variety of service jobs, particularly in restaurants and hotels and as parking lot attendants and taxi drivers.[12]

Ethiopian traditional medicine consists of indigenous magicoreligious practices and beliefs integrated with certain aspects of the Greco-Arabic tradition of medicine.[15-17] Currently in Ethiopia, both traditional Ethiopian medicine and Western cosmopolitan biomedicine are practiced, each being applied to specific illnesses. It is not uncommon to find Ethiopians using both systems of medicine simultaneously.

There are no traditional Ethiopian healers in the United States. This is because the Ethiopian immigrant community consists mostly of young urban people whereas the healing tradition is usually the domain of older people and religious leaders. Traditional medicine in Ethiopia, as in many other countries,[15,18,19] concerns both the prevention and cure of disease. Most Ethiopians place great reliance on religion and God, with prayers being used against illness and misfortune. Family members are important sources of assistance and comfort during periods of serious illness.

Telling Bad News in Ethiopia

The physician in case 1 felt that regardless of the family's wishes, it is a patient's right to know the diagnosis. The patient and her family were upset by the disclosure, however. One family member commented that the patient could have died of the shock from the bad news.

It is vital in Ethiopian culture that to break bad news such as grave illness or the death of a family member, an appropriate time, place, and way be chosen. A sudden shock is to be avoided at all cost, especially when dealing with children, the elderly, and sick people because of the harmful effects this news may have on people with fragile emotional states. The disclosure of bad news is staged, and close friends or family members prepare persons to face disturbing news by leading them to it gradually. The situation is discussed among friends and relatives to decide the appropriate time and the least frightening way of breaking the news. If it is a death or an accident involving a family member, the news is disclosed to close friends before a person is told so that they will be there to provide emotional support. For Ethiopians, it is important how tragic news is communicated to them. Tragic news is not told in the evening, unless it is something that needs immediate attention; even then, breaking the news is staged. For example, a typical way of informing a person of bad news such as the death of a family member who lives out of town is to break the news in the morning, at the person's residence and in the presence of close friends. Friends and relatives stay with the person, keeping him or her company, preparing food, and sometimes even staying overnight. Breaking tragic news in the evening will impose a long, sleepless night and add more hardship on all parties concerned.

For Ethiopians the extended family is the most important institution. Children remain deeply attached to their families and sensitive to the wishes of their parents. Obligations toward the family persist long after children have married and established families of their own.[20] During illness and crisis, Ethiopians rely heavily on family members to help them cope. Therefore, the role of the family and of friends is important for them. Families are responsible for managing the information and the illness experience of a family member during a period of illness. In cases of serious illness, physicians communicate little information to patients. Whatever the diagnosis, they are expected to tell the bad news to a family member first.

A family will judge how and when they want to let a patient know; this may vary with the age, level of understanding, and the emotional and physical condition of the sick person. In case 2, the family felt that a 16-year-old girl was too young and should not be burdened by the news of her impending death. Furthermore, in Ethiopian culture, sex is a private matter and children are socialized never to discuss sexual matters openly. The teenager in case 2 was caught between the expectations of two cultures.

Telling the Truth and the Effect on Hope

All societies seem to recognize the need for hope but differ in understanding the conditions for it. Offering hope is a form of caring that is embedded in a cultural context.[6,7,10] In the North American culture where the values of individualism, autonomy, and self-reliance are important, providing the "naked" truth about illness is seen as a way of giving patients hope. Disclosing all the facts gives patients a sense of control over their illness and allows them to help decide their fate. Furthermore, total possession of such information is a legal right. Diagnostic information regarding one's body and life belongs to the person about whom it refers, not to the family or the physician.[10,21]

In contrast, in traditional societies like Ethiopia, where the family's importance dominates over individual members', any information, including diagnostic facts, belongs to the family. The family then uses the information at its discretion for the benefit of the patient. In such societies, families tend to protect their ill members from knowing the gravity of a situation to maintain hope and the equilibrium of day-to-day living. Not knowing the gravity of a condition allows the patient to hold on to the hope of a cure. In these societies, the physician collaborates with the family in protecting the patient from such bad news.[6,7]

In Ethiopian culture, the patient and healer relationship is paternalistic and protective, and trust is a major component of this relationship. Moreover, Ethiopian traditional medicine, like many other traditional medical practices,[19] is mostly concerned with the act of healing the patient. All the attention of the healer is in the act of diagnosis, to find out who or what caused the illness and to remove the pathogenic agent. Prognosis has no dominance in the medical systems of traditional societies.[15,19] The current physician-patient relationship in Ethiopia is parallel to the relationship with indigenous healers. Ethiopian patients rely on their physicians to cure their illnesses and help them manage their pain. Most of all, they want to be reassured that they will get well. Disclosing a serious diagnosis with a poor prognosis conflicts with the hope for healing.

Moreover, it is taken for granted that physicians' actions

are always for the good of patients. An Ethiopian physician, for example, said that he will tell an Ethiopian patient who has a 40% chance of surviving with treatment that the disease is 100% treatable because Ethiopians seem to do better when reassured. Even if patients find out that what they were told is inconsistent with medical findings, Ethiopian patients are not going to question their physicians' honesty. Physicians' actions will be considered a form of caring. In contrast, Americans will consider this dishonest and may even pursue legal action.

Honesty is the most highly valued character trait in the Ethiopian culture. Truth is socially defined, however. In Ethiopia it is acceptable to employ deception in not wanting to tell a person something that will offend or hurt. In Ethiopian culture deception has its more subtle passive forms—deceiving by omitting the truth rather than committing a falsehood.[20] Furthermore, contrary to the American reliance on an explicit verbal communication of emotion, Ethiopians rely on nonverbal communication. Feelings are expressed by action and behavior; love and concern are rarely expressed verbally. Family members convey their love for each other by being protective of each other's feelings, protecting each other from suffering (emotional and physical), surrounding a person in a time of crisis, providing care, and believing in and encouraging the person to hold on to hope.

Although it appears to outsiders that patients are kept in the dark, in most terminal situations it is apparent that the patients know that death is imminent. After all, no one is more able than patients themselves to judge failing health. Contrary to the American concern of overtly preparing for death,[22] some cultures have a way of getting ready to die that does not have to be verbalized. For Ethiopians, however, preparing for their death does not affect their faith in hope, and any discussion of the impending death of a sick person is avoided by all parties involved until the end. For example, in case 1, although the patient and her family knew the extent of her illness, her family's and friends' efforts were to make sure that she continued to hold on to hope. Ethiopians strongly believe in destiny and in God's power to influence events, especially health events. Their persistence in holding on to hope is tied to their religious belief in God's miraculous powers. The Ethiopian Coptic Christian religion, for instance, places tremendous emphasis on Biblical stories of faith and miracles. Moreover, Ethiopian religious institutions play major roles in healing. Healers including priests and physicians are considered mediators of God's will. For an Ethiopian, giving up hope is against religious teachings and amounts to losing faith in God.

Furthermore, communicating openly about patients' terminal illnesses evokes strong emotional reactions in patients and their families. It also makes family members' imminent separation real. People are afraid that the emotional reaction will be difficult to deal with and may even interfere with the care of the dying. Ethiopian culture restrains most emotional outbursts except at the death of loved ones when great demonstrations of feeling are encouraged. Women tear their clothes and beat their chests to the point that they become sick with grief. Men are excused to cry out loud and shed tears. The loud crying of mourners continues for days after a funeral, revived periodically by the arrival of a close friend or relative who has just found out about the death. Crying at mourning in Ethiopia is collective. Members of a family have to help a newcomer express grief. Professional mourners are hired to stage the collective grieving. Although in the United States they do not hire professional mourners, Ethiopians' traditional grieving practices persist. There have been a few cases where the police were called by their American neighbors because the Ethiopians were disturbing the peace. On one occasion the mourners themselves were threatened with commitment to a mental hospital by the police unless they controlled themselves. In Ethiopian culture, death is the only time persons get to be honest with their feelings and have the uncontested right to express their pain to the whole world. Ethiopians are amazed by the Anglo-Saxon and Northern Europeans' stoic and restrained reactions to death.

Denying the knowledge of an imminent death is mutually understood by the patient and the family. Each is concerned for the well-being of the other and for easing the other's suffering. Even at the last moment of struggle, patients control their emotions to prevent their family from collapsing. The family struggles to do the same so that the patient will not be disturbed by the outburst of emotional reaction to the reality of death until it actually occurs. Indeed, family members are not allowed to cry in front of a dying person to prevent this potentially strong emotion from erupting. Suppressing the knowledge of the imminent death of a loved one is one way of delaying the emotional eruption until death occurs and of enabling the family to continue giving care to the dying patient.

Guidelines for Health Care Professionals

Although most physicians and nurses are overworked and have little time to pay attention and make adjustments to ethnic differences, a little effort in understanding these patients' needs will be gratifying. The following suggestions may help minimize some cross-cultural conflicts, at least for Ethiopian patients.

- Family is important for Ethiopians, and members work as a unit. Therefore, the family should be allowed to participate in a patient's care. Family members will rarely disagree with treatment procedures if they have placed their trust in the physician. While establishing the physician-patient relationship and before communicating a serious medical situation, ask the patient if a family member or a close friend can be designated as a spokesperson. Health professionals should be selective in imparting information to a member of the family; for example, avoid telling the mother or the wife because women are socialized to be fragile. In the absence of an immediate family member, ask for a close friend. Friendship ties are strong among Ethiopians and are even stronger when they are away from their homeland. Friends substitute for the extended family.
- Ethiopians often assess physicians more by the warmth of their manners than by a professional look. A few opening words and show of concern and interest in the patient's background will make a patient feel welcome. If the physician knows something, however trivial, about the refugee's country of origin or culture, mentioning it will break the ice.
- Many Ethiopians appear to be "Americanized," but usually this is superficial. The Ethiopian community is tightly knit, with people socializing mostly with each other, so their cultural values are continually being reinforced. Even those who have been in the United States for a long time and are fully acculturated professionals revert to their cultural roots in times of crisis. This was partly the source of the conflict in cases 1 and 2.

- Ethiopians gravitate to their physicians and their family for reassurance that they will make it through a crisis. Citing statistics or any evidence of a poor prognosis undercuts hope and the will to fight a disease. Partial disclosure seems to work better with these patients. Indeed, some physicians consider full disclosure to be neither possible nor therapeutic. They argue that controlling information is essential to sustain or instill an optimistic attitude in patients, especially those with a poor prognosis.[10] Patients should be reassured that they will make it through. Gloomy statistics can kill, whereas a positive attitude can heal.[23]
- Most Ethiopians have no knowledge of treatment procedures and are willing to let their physicians decide for them. Signing consent forms written for a middle-class American patient is not useful for a refugee who has no knowledge of medical procedures. It may actually induce anxiety. An Ethiopian physician commented that a frustrating experience in his training in American medical practice is in the use of informed consent. He thinks that American medical practice emphasizes the adverse possibilities, which only makes patients anxious. For example, a patient scheduled for an operation is awakened at 6 AM to sign a paper informing the patient of all the odds of not making it through the operation or other untoward events by listing the chances of dying of bleeding, anesthesia risks, and the like. Even though the chances of an adverse outcome are statistically low, what stays with the patient is the dismal information. In Ethiopia, consent for surgical treatment is signed by family members. Physicians here should consider having a designated family member sign such papers to help alleviate anxiety in the patient.
- Ethiopians' pattern of somatization of anxiety and depression and their negative attitudes toward psychiatry are similar to those of other immigrants from the Middle East.[24] Ethiopians resist seeking help from mental health counselors because of the stigma associated with mental illness in their culture. They do not reveal personal information easily and less so at the first clinical encounter. They are socialized to assume that it is improper to reveal oneself fully or to disclose personal secrets to anyone but a close friend. Privacy is further protected by the shared belief that others normally do not have a just claim to information about personal matters.[20] An Ethiopian interpreter said that it is difficult to explain to Ethiopians the need to reveal feelings to a physician. She said that a common Ethiopian phrase is "Just give me the medication and let me go. Why should I tell my life history to a stranger?" Reassuring the confidentiality of requested information is vital.
- Finally, the use of an interpreter is immensely important, not just to translate the medical history and procedures but to assist health care professionals to treat patients in culturally appropriate ways. Except among large groups, most interpreters from the same culture live in the same community, know the patient's family or friends, and cannot be neutral.[25] Much of the time they get caught in a conflicting situation, as in case 3 where there was an emotional conflict between the patient and the interpreter on one hand and on the other hand a cultural conflict between the interpreter and the physician caused by the physician's persistence in relating such distressing information on the spot. This situation could have been avoided by consulting with the interpreter ahead of time.

Judgments about what a dying patient should be told are embedded in cultural, social, and psychological patterns. The anticipated loss of a family member is a painful process that challenges the strengths and defenses of any family. Disclosure of a life-threatening illness is extremely difficult even in American culture.[10] It gets more complicated when the patient is a refugee who is simultaneously undergoing the stress of adapting to a new culture.[11] The physicians who are most successful in gaining the cooperation of refugee or immigrant patients are culturally sensitive to the patients' beliefs and practices.[26] Sensitivity to a refugee's worldview may reduce the frustration and conflict experienced by both refugees and American physicians.

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